

107TH CONGRESS  
1ST SESSION

# S. 382

To prohibit discrimination on the basis of genetic information with respect  
to health insurance.

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## IN THE SENATE OF THE UNITED STATES

FEBRUARY 15, 2001

Ms. SNOWE (for herself, Mr. FRIST, Mr. JEFFORDS, Ms. COLLINS, Mr.  
DEWINE, and Mr. ENZI) introduced the following bill; which was read  
twice and referred to the Committee on Health, Education, Labor, and  
Pensions

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## A BILL

To prohibit discrimination on the basis of genetic information  
with respect to health insurance.

1       *Be it enacted by the Senate and House of Representa-*  
2       *tives of the United States of America in Congress assembled,*

3       **SECTION 1. SHORT TITLE.**

4       This Act may be cited as the “Genetic Information  
5       Nondiscrimination in Health Insurance Act of 2001”.

1 **SEC. 2. AMENDMENTS TO EMPLOYEE RETIREMENT INCOME**  
 2 **SECURITY ACT OF 1974.**

3 (a) PROHIBITION OF HEALTH DISCRIMINATION ON  
 4 THE BASIS OF GENETIC INFORMATION OR GENETIC  
 5 SERVICES.—

6 (1) NO ENROLLMENT RESTRICTION FOR GE-  
 7 NETIC SERVICES.—Section 702(a)(1)(F) of the Em-  
 8 ployee Retirement Income Security Act of 1974 (29  
 9 U.S.C. 1182(a)(1)(F)) is amended by inserting be-  
 10 fore the period the following: “(including informa-  
 11 tion about a request for or receipt of genetic serv-  
 12 ices)”.

13 (2) NO DISCRIMINATION IN GROUP PREMIUMS  
 14 BASED ON PREDICTIVE GENETIC INFORMATION.—  
 15 Subpart B of part 7 of subtitle B of title I of the  
 16 Employee Retirement Income Security Act of 1974  
 17 (29 U.S.C. 1185 et seq.) is amended by adding at  
 18 the end the following:

19 **“SEC. 714. PROHIBITING PREMIUM DISCRIMINATION**  
 20 **AGAINST GROUPS ON THE BASIS OF PRE-**  
 21 **DICTIVE GENETIC INFORMATION.**

22 “A group health plan, or a health insurance issuer  
 23 offering group health insurance coverage in connection  
 24 with a group health plan, shall not adjust premium or con-  
 25 tribution amounts for a group on the basis of predictive  
 26 genetic information concerning an individual in the group

1 or a family member of the individual (including informa-  
 2 tion about a request for or receipt of genetic services).”.

3 (3) CONFORMING AMENDMENTS.—

4 (A) IN GENERAL.—Section 702(b) of the  
 5 Employee Retirement Income Security Act of  
 6 1974 (29 U.S.C. 1182(b)) is amended by add-  
 7 ing at the end the following:

8 “(3) REFERENCE TO RELATED PROVISION.—  
 9 For a provision prohibiting the adjustment of pre-  
 10 mium or contribution amounts for a group under a  
 11 group health plan on the basis of predictive genetic  
 12 information (including information about a request  
 13 for or receipt of genetic services), see section 714.”.

14 (B) TABLE OF CONTENTS.—The table of  
 15 contents in section 1 of the Employee Retirement  
 16 Income Security Act of 1974 is amended  
 17 by inserting after the item relating to section  
 18 713 the following new item:

“Sec. 714. Prohibiting premium discrimination against groups on the basis of  
 predictive genetic information.”.

19 (b) LIMITATION ON COLLECTION OF PREDICTIVE  
 20 GENETIC INFORMATION.—Section 702 of the Employee  
 21 Retirement Income Security Act of 1974 (29 U.S.C. 1182)  
 22 is amended by adding at the end the following:

23 “(c) COLLECTION OF PREDICTIVE GENETIC INFOR-  
 24 MATION.—

1           “(1) LIMITATION ON REQUESTING OR REQUIR-  
2           ING PREDICTIVE GENETIC INFORMATION.—Except  
3           as provided in paragraph (2), a group health plan,  
4           or a health insurance issuer offering health insur-  
5           ance coverage in connection with a group health  
6           plan, shall not request or require predictive genetic  
7           information concerning an individual or a family  
8           member of the individual (including information  
9           about a request for or receipt of genetic services).

10           “(2) INFORMATION NEEDED FOR DIAGNOSIS,  
11           TREATMENT, OR PAYMENT.—

12           “(A) IN GENERAL.—Notwithstanding para-  
13           graph (1), a group health plan, or a health in-  
14           surance issuer offering health insurance cov-  
15           erage in connection with a group health plan,  
16           that provides health care items and services to  
17           an individual or dependent may request (but  
18           may not require) that such individual or de-  
19           pendent disclose, or authorize the collection or  
20           disclosure of, predictive genetic information for  
21           purposes of diagnosis, treatment, or payment  
22           relating to the provision of health care items  
23           and services to such individual or dependent.

24           “(B) NOTICE OF CONFIDENTIALITY PRAC-  
25           TICES AND DESCRIPTION OF SAFEGUARDS.—As

a part of a request under subparagraph (A), the group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall provide to the individual or dependent a description of the procedures in place to safeguard the confidentiality, as described in subsection (d), of such predictive genetic information.

“(d) CONFIDENTIALITY WITH RESPECT TO PREDICTIVE GENETIC INFORMATION.—

“(1) NOTICE OF CONFIDENTIALITY PRACTICES.—A group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall post or provide, in writing and in a clear and conspicuous manner, notice of the plan or issuer’s confidentiality practices, that shall include—

“(A) a description of an individual’s rights with respect to predictive genetic information;

“(B) the procedures established by the plan or issuer for the exercise of the individual’s rights; and

“(C) the right to obtain a copy of the notice of the confidentiality practices required under this subsection.

1           “(2) ESTABLISHMENT OF SAFEGUARDS.—A  
 2           group health plan, or a health insurance issuer offer-  
 3           ing health insurance coverage in connection with a  
 4           group health plan, shall establish and maintain ap-  
 5           propriate administrative, technical, and physical  
 6           safeguards to protect the confidentiality, security,  
 7           accuracy, and integrity of predictive genetic informa-  
 8           tion created, received, obtained, maintained, used,  
 9           transmitted, or disposed of by such plan or issuer.

10           “(3) COMPLIANCE WITH CERTAIN STAND-  
 11           ARDS.—With respect to the establishment and main-  
 12           tenance of safeguards under this subsection or sub-  
 13           section (c)(2)(B), a group health plan, or a health  
 14           insurance issuer offering health insurance coverage  
 15           in connection with a group health plan, shall be  
 16           deemed to be in compliance with such subsections if  
 17           such plan or issuer is in compliance with the stand-  
 18           ards promulgated by the Secretary of Health and  
 19           Human Services under—

20                   “(A) part C of title XI of the Social Secu-  
 21                   rity Act (42 U.S.C. 1320d et seq.); or

22                   “(B) section 264(c) of Health Insurance  
 23                   Portability and Accountability Act of 1996  
 24                   (Public Law 104–191; 110 Stat. 2033).”.

1 (c) DEFINITIONS.—Section 733(d) of the Employee  
 2 Retirement Income Security Act of 1974 (29 U.S.C.  
 3 1191b(d)) is amended by adding at the end the following:

4 “(5) FAMILY MEMBER.—The term ‘family  
 5 member’ means with respect to an individual—

6 “(A) the spouse of the individual;

7 “(B) a dependent child of the individual,  
 8 including a child who is born to or placed for  
 9 adoption with the individual; and

10 “(C) all other individuals related by blood  
 11 to the individual or the spouse or child de-  
 12 scribed in subparagraph (A) or (B).

13 “(6) GENETIC INFORMATION.—The term ‘ge-  
 14 netic information’ means information about genes,  
 15 gene products, or inherited characteristics that may  
 16 derive from an individual or a family member (in-  
 17 cluding information about a request for or receipt of  
 18 genetic services).

19 “(7) GENETIC SERVICES.—The term ‘genetic  
 20 services’ means health services provided to obtain,  
 21 assess, or interpret genetic information for diag-  
 22 nostic and therapeutic purposes, and for genetic  
 23 education and counseling.

24 “(8) PREDICTIVE GENETIC INFORMATION.—

“(A) IN GENERAL.—The term ‘predictive genetic information’ means, in the absence of symptoms, clinical signs, or a diagnosis of the condition related to such information—

“(i) information about an individual’s genetic tests;

“(ii) information about genetic tests of family members of the individual; or

“(iii) information about the occurrence of a disease or disorder in family members.

“(B) EXCEPTIONS.—The term ‘predictive genetic information’ shall not include—

“(i) information about the sex or age of the individual;

“(ii) information derived from physical tests, such as the chemical, blood, or urine analyses of the individual including cholesterol tests; and

“(iii) information about physical exams of the individual.

“(9) GENETIC TEST.—The term ‘genetic test’ means the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites, including analysis of genotypes, mutations, phenotypes, or



1 karyotypes, for the purpose of predicting risk of dis-  
 2 ease in asymptomatic or undiagnosed individuals.  
 3 Such term does not include physical tests, such as  
 4 the chemical, blood, or urine analyses of the indi-  
 5 vidual including cholesterol tests, and physical exams  
 6 of the individual, in order to detect symptoms, clin-  
 7 ical signs, or a diagnosis of disease.”.

8 (d) EFFECTIVE DATE.—Except as provided in this  
 9 section, this section and the amendments made by this  
 10 section shall apply with respect to group health plans for  
 11 plan years beginning 1 year after the date of the enact-  
 12 ment of this Act.

13 **SEC. 3. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**  
 14 **ACT.**

15 (a) AMENDMENTS RELATING TO THE GROUP MAR-  
 16 KET.—

17 (1) PROHIBITION OF HEALTH DISCRIMINATION  
 18 ON THE BASIS OF GENETIC INFORMATION IN THE  
 19 GROUP MARKET.—

20 (A) NO ENROLLMENT RESTRICTION FOR  
 21 GENETIC SERVICES.—Section 2702(a)(1)(F) of  
 22 the Public Health Service Act (42 U.S.C.  
 23 300gg–1(a)(1)(F)) is amended by inserting be-  
 24 fore the period the following: “(including infor-

1           mation about a request for or receipt of genetic  
2           services)’’.

3           (B) NO DISCRIMINATION IN PREMIUMS  
4           BASED ON PREDICTIVE GENETIC INFORMA-  
5           TION.—Subpart 2 of part A of title XXVII of  
6           the Public Health Service Act (42 U.S.C.  
7           300gg–4 et seq.) is amended by adding at the  
8           end the following new section:

9   **“SEC. 2707. PROHIBITING PREMIUM DISCRIMINATION**  
10           **AGAINST GROUPS ON THE BASIS OF PRE-**  
11           **DICTIVE GENETIC INFORMATION IN THE**  
12           **GROUP MARKET.**

13       “A group health plan, or a health insurance issuer  
14 offering group health insurance coverage in connection  
15 with a group health plan shall not adjust premium or con-  
16 tribution amounts for a group on the basis of predictive  
17 genetic information concerning an individual in the group  
18 or a family member of the individual (including informa-  
19 tion about a request for or receipt of genetic services).’’.

20           (C) CONFORMING AMENDMENT.—Section  
21           2702(b) of the Public Health Service Act (42  
22           U.S.C. 300gg–1(b)) is amended by adding at  
23           the end the following:

24       “(3) REFERENCE TO RELATED PROVISION.—  
25       For a provision prohibiting the adjustment of pre-

mium or contribution amounts for a group under a group health plan on the basis of predictive genetic information (including information about a request for or receipt of genetic services), see section 2707.”.

(D) LIMITATION ON COLLECTION AND DIS-

CLOSURE OF PREDICTIVE GENETIC INFORMA-

TION.—Section 2702 of the Public Health Serv-

ice Act (42 U.S.C. 300gg–1) is amended by

adding at the end the following:

“(c) COLLECTION OF PREDICTIVE GENETIC INFOR-

MATION.—

“(1) LIMITATION ON REQUESTING OR REQUIR-

ING PREDICTIVE GENETIC INFORMATION.—Except

as provided in paragraph (2), a group health plan,

or a health insurance issuer offering health insur-

ance coverage in connection with a group health

plan, shall not request or require predictive genetic

information concerning an individual or a family

member of the individual (including information

about a request for or receipt of genetic services).

“(2) INFORMATION NEEDED FOR DIAGNOSIS,

TREATMENT, OR PAYMENT.—

“(A) IN GENERAL.—Notwithstanding para-

graph (1), a group health plan, or a health in-

surance issuer offering health insurance cov-

erage in connection with a group health plan,  
 that provides health care items and services to  
 an individual or dependent may request (but  
 may not require) that such individual or de-  
 pendent disclose, or authorize the collection or  
 disclosure of, predictive genetic information for  
 purposes of diagnosis, treatment, or payment  
 relating to the provision of health care items  
 and services to such individual or dependent.

“(B) NOTICE OF CONFIDENTIALITY PRAC-  
 TICES AND DESCRIPTION OF SAFEGUARDS.—As  
 a part of a request under subparagraph (A),  
 the group health plan, or a health insurance  
 issuer offering health insurance coverage in  
 connection with a group health plan, shall pro-  
 vide to the individual or dependent a descrip-  
 tion of the procedures in place to safeguard the  
 confidentiality, as described in subsection (d),  
 of such predictive genetic information.

“(d) CONFIDENTIALITY WITH RESPECT TO PRE-  
 DICTIVE GENETIC INFORMATION.—

“(1) NOTICE OF CONFIDENTIALITY PRAC-  
 TICES.—A group health plan, or a health insurance  
 issuer offering health insurance coverage in connec-  
 tion with a group health plan, shall post or provide,

1 in writing and in a clear and conspicuous manner,  
2 notice of the plan or issuer's confidentiality prac-  
3 tices, that shall include—

4 “(A) a description of an individual's rights  
5 with respect to predictive genetic information;

6 “(B) the procedures established by the  
7 plan or issuer for the exercise of the individ-  
8 ual's rights; and

9 “(C) the right to obtain a copy of the no-  
10 tice of the confidentiality practices required  
11 under this subsection.

12 “(2) ESTABLISHMENT OF SAFEGUARDS.—A  
13 group health plan, or a health insurance issuer offer-  
14 ing health insurance coverage in connection with a  
15 group health plan, shall establish and maintain ap-  
16 propriate administrative, technical, and physical  
17 safeguards to protect the confidentiality, security,  
18 accuracy, and integrity of predictive genetic informa-  
19 tion created, received, obtained, maintained, used,  
20 transmitted, or disposed of by such plan or issuer.

21 “(3) COMPLIANCE WITH CERTAIN STAND-  
22 ARDS.—With respect to the establishment and main-  
23 tenance of safeguards under this subsection or sub-  
24 section (c)(2)(B), a group health plan, or a health  
25 insurance issuer offering health insurance coverage

1 in connection with a group health plan, shall be  
 2 deemed to be in compliance with such subsections if  
 3 such plan or issuer is in compliance with the stand-  
 4 ards promulgated by the Secretary of Health and  
 5 Human Services under—

6 “(A) part C of title XI of the Social Secu-  
 7 rity Act (42 U.S.C. 1320d et seq.); or

8 “(B) section 264(c) of Health Insurance  
 9 Portability and Accountability Act of 1996  
 10 (Public Law 104–191; 110 Stat. 2033).”.

11 (2) DEFINITIONS.—Section 2791(d) of the Pub-  
 12 lic Health Service Act (42 U.S.C. 300gg–91(d)) is  
 13 amended by adding at the end the following:

14 “(15) FAMILY MEMBER.—The term ‘family  
 15 member’ means, with respect to an individual—

16 “(A) the spouse of the individual;

17 “(B) a dependent child of the individual,  
 18 including a child who is born to or placed for  
 19 adoption with the individual; and

20 “(C) all other individuals related by blood  
 21 to the individual or the spouse or child de-  
 22 scribed in subparagraph (A) or (B).

23 “(16) GENETIC INFORMATION.—The term ‘ge-  
 24 netic information’ means information about genes,  
 25 gene products, or inherited characteristics that may

1       derive from an individual or a family member (in-  
 2       cluding information about a request for or receipt of  
 3       genetic services).

4           “(17) GENETIC SERVICES.—The term ‘genetic  
 5       services’ means health services provided to obtain,  
 6       assess, or interpret genetic information for diag-  
 7       nostic and therapeutic purposes, and for genetic  
 8       education and counseling.

9           “(18) PREDICTIVE GENETIC INFORMATION.—

10           “(A) IN GENERAL.—The term ‘predictive  
 11       genetic information’ means, in the absence of  
 12       symptoms, clinical signs, or a diagnosis of the  
 13       condition related to such information—

14           “(i) information about an individual’s  
 15       genetic tests;

16           “(ii) information about genetic tests  
 17       of family members of the individual; or

18           “(iii) information about the occur-  
 19       rence of a disease or disorder in family  
 20       members.

21           “(B) EXCEPTIONS.—The term ‘predictive  
 22       genetic information’ shall not include—

23           “(i) information about the sex or age  
 24       of the individual;

1                   “(ii) information derived from phys-  
 2                   ical tests, such as the chemical, blood, or  
 3                   urine analyses of the individual including  
 4                   cholesterol tests; and

5                   “(iii) information about physical  
 6                   exams of the individual.

7                   “(19) GENETIC TEST.—The term ‘genetic test’  
 8                   means the analysis of human DNA, RNA, chro-  
 9                   mosomes, proteins, and certain metabolites, includ-  
 10                  ing analysis of genotypes, mutations, phenotypes, or  
 11                  karyotypes, for the purpose of predicting risk of dis-  
 12                  ease in asymptomatic or undiagnosed individuals.  
 13                  Such term does not include physical tests, such as  
 14                  the chemical, blood, or urine analyses of the indi-  
 15                  vidual including cholesterol tests, and physical exams  
 16                  of the individual, in order to detect symptoms, clin-  
 17                  ical signs, or a diagnosis of disease.”.

18                  (b) AMENDMENT RELATING TO THE INDIVIDUAL  
 19 MARKET.—The first subpart 3 of part B of title XXVII  
 20 of the Public Health Service Act (42 U.S.C. 300gg–51 et  
 21 seq.) (relating to other requirements) is amended—

22                   (1) by redesignating such subpart as subpart 2;

23                   and

24                   (2) by adding at the end the following:



1   **“SEC. 2753. PROHIBITION OF HEALTH DISCRIMINATION ON**  
 2                           **THE BASIS OF PREDICTIVE GENETIC INFOR-**  
 3                           **MATION.**

4           “(a) PROHIBITION ON PREDICTIVE GENETIC INFOR-  
 5 MATION AS A CONDITION OF ELIGIBILITY.—A health in-  
 6 surance issuer offering health insurance coverage in the  
 7 individual market may not use predictive genetic informa-  
 8 tion as a condition of eligibility of an individual to enroll  
 9 in individual health insurance coverage (including infor-  
 10 mation about a request for or receipt of genetic services).

11          “(b) PROHIBITION ON PREDICTIVE GENETIC INFOR-  
 12 MATION IN SETTING PREMIUM RATES.—A health insur-  
 13 ance issuer offering health insurance coverage in the indi-  
 14 vidual market shall not adjust premium rates for individ-  
 15 uals on the basis of predictive genetic information con-  
 16 cerning such an enrollee or a family member of the en-  
 17 rollee (including information about a request for or receipt  
 18 of genetic services).

19          “(c) COLLECTION OF PREDICTIVE GENETIC INFOR-  
 20 MATION.—

21               “(1) LIMITATION ON REQUESTING OR REQUIR-  
 22 ING PREDICTIVE GENETIC INFORMATION.—Except  
 23 as provided in paragraph (2), a health insurance  
 24 issuer offering health insurance coverage in the indi-  
 25 vidual market shall not request or require predictive  
 26 genetic information concerning an individual or a

1 family member of the individual (including informa-  
2 tion about a request for or receipt of genetic serv-  
3 ices).

4 “(2) INFORMATION NEEDED FOR DIAGNOSIS,  
5 TREATMENT, OR PAYMENT.—

6 “(A) IN GENERAL.—Notwithstanding para-  
7 graph (1), a health insurance issuer offering  
8 health insurance coverage in the individual mar-  
9 ket that provides health care items and services  
10 to an individual or dependent may request (but  
11 may not require) that such individual or de-  
12 pendent disclose, or authorize the collection or  
13 disclosure of, predictive genetic information for  
14 purposes of diagnosis, treatment, or payment  
15 relating to the provision of health care items  
16 and services to such individual or dependent.

17 “(B) NOTICE OF CONFIDENTIALITY PRAC-  
18 TICES AND DESCRIPTION OF SAFEGUARDS.—As  
19 a part of a request under subparagraph (A),  
20 the health insurance issuer offering health in-  
21 surance coverage in the individual market shall  
22 provide to the individual or dependent a de-  
23 scription of the procedures in place to safe-  
24 guard the confidentiality, as described in sub-

1           section (d), of such predictive genetic informa-  
2           tion.

3           “(d) CONFIDENTIALITY WITH RESPECT TO PRE-  
4           DICTIVE GENETIC INFORMATION.—

5           “(1) NOTICE OF CONFIDENTIALITY PRAC-  
6           TICES.—A health insurance issuer offering health in-  
7           surance coverage in the individual market shall post  
8           or provide, in writing and in a clear and conspicuous  
9           manner, notice of the issuer’s confidentiality prac-  
10          tices, that shall include—

11                   “(A) a description of an individual’s rights  
12                   with respect to predictive genetic information;

13                   “(B) the procedures established by the  
14                   issuer for the exercise of the individual’s rights;  
15                   and

16                   “(C) the right to obtain a copy of the no-  
17                   tice of the confidentiality practices required  
18                   under this subsection.

19           “(2) ESTABLISHMENT OF SAFEGUARDS.—A  
20           health insurance issuer offering health insurance  
21           coverage in the individual market shall establish and  
22           maintain appropriate administrative, technical, and  
23           physical safeguards to protect the confidentiality, se-  
24           curity, accuracy, and integrity of predictive genetic

information created, received, obtained, maintained,  
used, transmitted, or disposed of by such issuer.

“(3) COMPLIANCE WITH CERTAIN STANDARDS.—With respect to the establishment and maintenance of safeguards under this subsection or subsection (c)(2)(B), a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall be deemed to be in compliance with such subsections if such plan or issuer is in compliance with the standards promulgated by the Secretary of Health and Human Services under—

“(A) part C of title XI of the Social Security Act (42 U.S.C. 1320d et seq.); or

“(B) section 264(c) of Health Insurance Portability and Accountability Act of 1996 (Public Law 104–191; 110 Stat. 2033).”.

(c) EFFECTIVE DATE.—The amendments made by this section shall apply with respect to—

(1) group health plans, and health insurance coverage offered in connection with group health plans, for plan years beginning after 1 year after the date of enactment of this Act; and

(2) health insurance coverage offered, sold, issued, renewed, in effect, or operated in the indi-

1       vidual market after 1 year after the date of enact-  
2       ment of this Act.

3   **SEC. 4. AMENDMENTS TO THE INTERNAL REVENUE CODE**  
4       **OF 1986.**

5       (a) PROHIBITION OF HEALTH DISCRIMINATION ON  
6 THE BASIS OF GENETIC INFORMATION OR GENETIC  
7 SERVICES.—

8           (1) NO ENROLLMENT RESTRICTION FOR GE-  
9       NETIC SERVICES.—Section 9802(a)(1)(F) of the In-  
10      ternal Revenue Code of 1986 is amended by insert-  
11      ing before the period the following: “(including in-  
12      formation about a request for or receipt of genetic  
13      services)”.

14          (2) NO DISCRIMINATION IN GROUP PREMIUMS  
15      BASED ON PREDICTIVE GENETIC INFORMATION.—

16           (A) IN GENERAL.—Subchapter B of chap-  
17      ter 100 of the Internal Revenue Code of 1986  
18      is amended by adding at the end the following:

19   **“SEC. 9813. PROHIBITING PREMIUM DISCRIMINATION**  
20       **AGAINST GROUPS ON THE BASIS OF PRE-**  
21       **DICTIVE GENETIC INFORMATION.**

22      “A group health plan shall not adjust premium or  
23      contribution amounts for a group on the basis of predictive  
24      genetic information concerning an individual in the group

1 or a family member of the individual (including informa-  
 2 tion about a request for or receipt of genetic services).”.

3 (B) CONFORMING AMENDMENT.—Section  
 4 9802(b) of the Internal Revenue Code of 1986  
 5 is amended by adding at the end the following:

6 “(3) REFERENCE TO RELATED PROVISION.—  
 7 For a provision prohibiting the adjustment of pre-  
 8 mium or contribution amounts for a group under a  
 9 group health plan on the basis of predictive genetic  
 10 information (including information about a request  
 11 for or the receipt of genetic services), see section  
 12 9813.”.

13 (C) AMENDMENT TO TABLE OF SEC-  
 14 TIONS.—The table of sections for subchapter B  
 15 of chapter 100 of the Internal Revenue Code of  
 16 1986 is amended by adding at the end the fol-  
 17 lowing:

“Sec. 9813. Prohibiting premium discrimination against groups on the basis of  
 predictive genetic information.”.

18 (b) LIMITATION ON COLLECTION OF PREDICTIVE  
 19 GENETIC INFORMATION.—Section 9802 of the Internal  
 20 Revenue Code of 1986 is amended by adding at the end  
 21 the following:

22 “(d) COLLECTION OF PREDICTIVE GENETIC INFOR-  
 23 MATION.—

1           “(1) LIMITATION ON REQUESTING OR REQUIR-  
2           ING PREDICTIVE GENETIC INFORMATION.—Except  
3           as provided in paragraph (2), a group health plan  
4           shall not request or require predictive genetic infor-  
5           mation concerning an individual or a family member  
6           of the individual (including information about a re-  
7           quest for or receipt of genetic services).

8           “(2) INFORMATION NEEDED FOR DIAGNOSIS,  
9           TREATMENT, OR PAYMENT.—

10           “(A) IN GENERAL.—Notwithstanding para-  
11           graph (1), a group health plan that provides  
12           health care items and services to an individual  
13           or dependent may request (but may not re-  
14           quire) that such individual or dependent dis-  
15           close, or authorize the collection or disclosure  
16           of, predictive genetic information for purposes  
17           of diagnosis, treatment, or payment relating to  
18           the provision of health care items and services  
19           to such individual or dependent.

20           “(B) NOTICE OF CONFIDENTIALITY PRAC-  
21           TICES; DESCRIPTION OF SAFEGUARDS.—As a  
22           part of a request under subparagraph (A), the  
23           group health plan shall provide to the individual  
24           or dependent a description of the procedures in  
25           place to safeguard the confidentiality, as de-

1           scribed in subsection (e), of such predictive ge-  
 2           netic information.

3           “(e) CONFIDENTIALITY WITH RESPECT TO PRE-  
 4   DICTIVE GENETIC INFORMATION.—

5           “(1) NOTICE OF CONFIDENTIALITY PRAC-  
 6   TICES.—A group health plan shall post or provide,  
 7   in writing and in a clear and conspicuous manner,  
 8   notice of the plan’s confidentiality practices, that  
 9   shall include—

10           “(A) a description of an individual’s rights  
 11   with respect to predictive genetic information;

12           “(B) the procedures established by the  
 13   plan for the exercise of the individual’s rights;  
 14   and

15           “(C) the right to obtain a copy of the no-  
 16   tice of the confidentiality practices required  
 17   under this subsection.

18           “(2) ESTABLISHMENT OF SAFEGUARDS.—A  
 19   group health plan shall establish and maintain ap-  
 20   propriate administrative, technical, and physical  
 21   safeguards to protect the confidentiality, security,  
 22   accuracy, and integrity of predictive genetic informa-  
 23   tion created, received, obtained, maintained, used,  
 24   transmitted, or disposed of by such plan.



1           “(3) COMPLIANCE WITH CERTAIN STAND-  
 2       ARDS.—With respect to the establishment and main-  
 3       tenance of safeguards under this subsection or sub-  
 4       section (d)(2)(B), a group health plan, or a health  
 5       insurance issuer offering health insurance coverage  
 6       in connection with a group health plan, shall be  
 7       deemed to be in compliance with such subsections if  
 8       such plan or issuer is in compliance with the stand-  
 9       ards promulgated by the Secretary of Health and  
 10      Human Services under—

11               “(A) part C of title XI of the Social Secu-  
 12              rity Act (42 U.S.C. 1320d et seq.); or

13               “(B) section 264(c) of Health Insurance  
 14              Portability and Accountability Act of 1996  
 15              (Public Law 104–191; 110 Stat. 2033).”.

16      (c) DEFINITIONS.—Section 9832(d) of the Internal  
 17      Revenue Code of 1986 is amended by adding at the end  
 18      the following:

19               “(6) FAMILY MEMBER.—The term ‘family  
 20              member’ means, with respect to an individual—

21                      “(A) the spouse of the individual;

22                      “(B) a dependent child of the individual,  
 23              including a child who is born to or placed for  
 24              adoption with the individual; and

1           “(C) all other individuals related by blood  
2           to the individual or the spouse or child de-  
3           scribed in subparagraph (A) or (B).

4           “(7) GENETIC INFORMATION.—The term ‘ge-  
5           netic information’ means information about genes,  
6           gene products, or inherited characteristics that may  
7           derive from an individual or a family member (in-  
8           cluding information about a request for or receipt of  
9           genetic services).

10          “(8) GENETIC SERVICES.—The term ‘genetic  
11          services’ means health services provided to obtain,  
12          assess, or interpret genetic information for diag-  
13          nostic and therapeutic purposes, and for genetic  
14          education and counseling.

15          “(9) PREDICTIVE GENETIC INFORMATION.—

16               “(A) IN GENERAL.—The term ‘predictive  
17               genetic information’ means, in the absence of  
18               symptoms, clinical signs, or a diagnosis of the  
19               condition related to such information—

20                       “(i) information about an individual’s  
21                       genetic tests;

22                       “(ii) information about genetic tests  
23                       of family members of the individual; or

1                   “(iii) information about the occur-  
 2                   rence of a disease or disorder in family  
 3                   members.

4                   “(B) EXCEPTIONS.—The term ‘predictive  
 5                   genetic information’ shall not include—

6                   “(i) information about the sex or age  
 7                   of the individual;

8                   “(ii) information derived from phys-  
 9                   ical tests, such as the chemical, blood, or  
 10                  urine analyses of the individual including  
 11                  cholesterol tests; and

12                  “(iii) information about physical  
 13                  exams of the individual.

14                  “(10) GENETIC TEST.—The term ‘genetic test’  
 15                  means the analysis of human DNA, RNA, chro-  
 16                  mosomes, proteins, and certain metabolites, includ-  
 17                  ing analysis of genotypes, mutations, phenotypes, or  
 18                  karyotypes, for the purpose of predicting risk of dis-  
 19                  ease in asymptomatic or undiagnosed individuals.  
 20                  Such term does not include physical tests, such as  
 21                  the chemical, blood, or urine analyses of the indi-  
 22                  vidual including cholesterol tests, and physical exams  
 23                  of the individual, in order to detect symptoms, clin-  
 24                  ical signs, or a diagnosis of disease.”.

1       (d) EFFECTIVE DATE.—Except as provided in this  
2 section, this section and the amendments made by this  
3 section shall apply with respect to group health plans for  
4 plan years beginning after 1 year after the date of the  
5 enactment of this Act.

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